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Submission to the review of the Disability Support Pension Impairment Tables

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Acknowledgments

Inclusion Australia acknowledges the traditional owners of the land on which this publication was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples. We extend our respects to community members and Elders past and present.

Inclusion Australia recognises the efforts of self-advocates who have courageously told their stories and worked tirelessly over the years for equality and human rights for all.

This submission was prepared by Inclusion Australia. To write this submission, we listened to the voices and concerns of people with intellectual disability and their families and advocates.

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About Inclusion Australia

Inclusion Australia (IA) is the national peak body for intellectual disability. Previously known as the National Council on Intellectual Disability (NCID), IA was founded in 1954. IA's mission is to work to ensure people with intellectual disability have the same opportunities as people without disability.

IA is a federated body with state agencies in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia. Those agencies are: Council for Intellectual Disability (NSW), Parent 2 Parent (Qld), the South Australian Council on Intellectual Disability (SA), the Speak Out Association of Tasmania (Tas), the Victorian Advocacy League for Individuals with Disability (Vic), and Developmental Disability Western Australia (WA).

Introduction

Inclusion Australia, as the national peak body for people with intellectual disability, has a deep understanding of the challenges experienced when seeking jobs, earning a living and seeking the Disability Support Pension (DSP) and other entitlements. We welcome the opportunity to contribute to the Review of the DSP Impairment Tables.

IA has a long history of expertise in the employment sector and has advocated for people with intellectual disability in the Disability Support Pension. IA was closely involved in the 2011 review of the DSP Impairment Tables and contributed to the McClure Review of Australia's Welfare System in 2014. The present submission is based on its experience and is informed by people with intellectual disability and their supporters. Direct quotes from the intellectual disability community are included throughout.

To write the submission, we listened to people with intellectual disability, their families, carers and supporters. This included listening to Inclusion Australia's Our Voice sub-committee of people with intellectual disability, and surveys where we asked people about their experiences of DSP and related employment issues. People with intellectual disability, parents and other family members, advocates, and other supporters responded to the surveys. We thank them all for sharing their experiences and allowing us to use their comments in this submission.

While we understand this review is only looking at the Impairment Tables, these Tables are part of the greater DSP application experience, and our submission will sometimes speak in more general terms.

The experiences of people with intellectual disability applying for the DSP

Intellectual disability is a permanent lifelong condition. People with intellectual disability are usually diagnosed in early childhood. People with intellectual disability (defined as an IQ of less than 70) are considered to have ‘manifest eligibility’ for DSP – they are automatically eligible without having to meet other requirements for DSP. Yet government systems, including DSP, require people with intellectual disability to provide current evidence of their disability from a health practitioner in order to be eligible. This creates great emotional and financial strain on people with intellectual disability and their families and carers. It also creates an unnecessary administrative and cost burden on the health system and on Centrelink itself.

Government needs to acknowledge the lifelong nature of intellectual disability and re-design Centrelink systems, including the DSP, so they work in ways that reduce the need for unnecessary reviews that require proof of disability.

Getting onto the DSP

People with intellectual disability often find it very hard to get the DSP. They and their families, carers and supporters told us about their experiences and the kinds of difficulties they experienced.

Impairment Tables

Since 2012, Centrelink has used ‘impairment tables’ as a tool to help them decide if a person, who doesn’t meet the manifest rules, is eligible for DSP. The tables are used to assess how your condition affects your ability to do things such as walking, lifting or concentrating. Centrelink uses the tables to calculate a score based on how your condition affects your ability to work. To get DSP, you need to have a score of at least 20 points, which Centrelink says is a ‘severe functional impact’. If a person has more than one condition, these are assessed separately; if they don’t consider one of the conditions to be ‘fully diagnosed, treated and stabilised’ then a person with multiple disabilities requiring significant support may not score highly enough on the scales to get the DSP.

“When a person scores dramatically differently across domains, e.g. high in some areas, but low in others, this skews the results.”

There are other requirements to fulfil, even if you score at least 20 points on the impairment table rating, such as attending a Program of Support (to learn work readiness skills) for 18 months. And, if a person is assessed as being able to work at least 15 hours a week, they just aren’t considered eligible for DSP.

Transition to DSP at age 16

When children with intellectual disability turn 16, Centrelink automatically stops the Carer Allowance or Payment for their parent/carer. Parents have already provided evidence of their child’s intellectual disability and level of support needs to be eligible for these payments. At 16, parents must re-apply for their carer payments and also apply for DSP for their son or daughter. However,

Centrelink does not let families know that this will be happening nor that their child will need to go through a new eligibility process to get the DSP. For young people with intellectual disability, as well as new forms to fill in, this involves a psychological assessment to determine their IQ. Centrelink will not accept IQ reports done when a child is aged under 12 years (which would be most people with intellectual disability), and some families would never have received an IQ report. A school psychologist can do the assessment, but families may not realise this, and some schools resist doing a report for a non-educational purpose. So, they need to find a substantial amount of money to pay for an assessment and there is usually a significant wait time. In the meantime, they don't get their carer allowance or payment. This is very distressing, and parents say they don't understand why they again have to provide evidence to 'prove' their child has a disability, especially when their child has a very obvious lifelong disability such as Down syndrome.

"There seems to be a constant need to prove that the disability has not magically disappeared. There is an onus of proof placed upon the recipient of DSP and their family."

Centrelink needs to let families know that they should apply and how to apply for DSP in the lead up to their child turning 16, so they can begin the application and eligibility process and have a smooth transition to DSP. When a child's parent/carer has already been receiving a Carer Allowance or Payment, based on the child's diagnosis of intellectual disability, there should be no need for repeated IQ testing to show eligibility for the DSP.

Manifest eligibility

Some families said that the manifest condition rules were effective, and had saved them from having to provide further evidence of their son or daughter's disability in order to get DSP. But others said the rules were challenging and unfair for people whose IQ testing was 'borderline', just a few points over the cut-off point of 70, but who still need as much support. These people said they had to go through long and onerous processes to prove eligibility for DSP.

Borderline intellectual disability

"It (borderline intellectual disability) can be very difficult and hard to prove. Most parents give up with the constant rejections."

"Success seems to vary, depending on who processes the application."

People told Inclusion Australia that there are issues that specifically affect people with mild or borderline intellectual disability when they apply for the DSP. These include that:

- Some people don't realise they may be eligible,
- The forms are hard to understand and fill in (and people may be less likely to have family or other support),
- It is even harder to get the evidence they need,

- People who helped their students to apply for DSP saw varying success that didn't reflect each person's IQ and support needs.

Getting evidence to show you are eligible for DSP

Almost all the people with intellectual disability, their families, carers and supporters we consulted with said people often face problems when trying to provide sufficient evidence to show they are eligible for the DSP. This included getting evidence that Centrelink will accept, such as an up-to-date IQ score for older people with intellectual disability. Most people only have old childhood reports, or no reports, and need to get and pay for a new assessment.

Here is what people had to say about the difficulties they face providing evidence:

"Needing to provide a recent report is costly (\$2000+) and the waitlists are in excess of 6 months."

"It's hard to get an assessment. Psychologists won't do an assessment just for a DSP application. They have to have valid and substantiated reasons to do the assessment."

"Centrelink won't even acknowledge the impairment without an IQ score, despite all the other evidence stating that the intellectual disability is significant enough. It's a huge barrier."

There are specific frustrations around needing to continually prove their lifelong disability:

"IQ doesn't change, so it's frustrating that people have to prove their disability many times"

"Intellectual disability doesn't disappear!"

People said that Centrelink isn't clear about what evidence people need to provide. Applicants provide medical reports and doctors' letters, but these are often knocked back by Centrelink.

"The assessments are called into question by unqualified people. A public servant going over the reports often questions you (the carer) about the report that has been compiled by a qualified person. You then feel you have to prove your loved one is disabled enough and it causes a lot of stress."

People also said that Centrelink staff don't understand intellectual disability and this affects decisions about eligibility.

"They suggested that intellectual disability doesn't impact certain areas of life, such as mobility and personal care."

"For people with intellectual disability and families having to say your story repeatedly to people that often have limited understanding of the people they are assessing is frustrating."

Assessments

People with intellectual disability communicate in many different ways. Many people can only be understood by people who know them well. Real communication with people with intellectual disability takes time, understanding and expertise. The impairment table assessment process (and other Centrelink assessments such as Job Capacity Assessments), don't take into account people who don't use speech to communicate (or people from different cultural backgrounds), and there is no opportunity to spend time to get to know the person. People may also be anxious or fearful of the assessments and of 'failing' them. Assessors also don't understand that acquiescence¹ is common; that is, many people with intellectual disability will tend to go along with what is asked or suggested, or say what they think the person wants to hear.

One parent shared this example:

Assessor: "Do you use public transport?"

Person with intellectual disability: "Yes."

The assessor ticks the box.

Mum interjects, "Yes they use public transport, fully supported by myself or an Education Assistant... So no, they don't 'use' public transport independently."

Others questioned the suitability of assessment tools, such as IQ testing that relies on a person using speech, and Job Capacity Assessments that appeared to use the same tool no matter the person's disability.

Job Capacity Assessments to assess whether a person is eligible for support from a DES provider are carried out via a series of general questions. Yet a person's capacity to work depends on the kind of job, the supports they have, and whether there are barriers to them doing the job.

All of these factors unfairly affect the validity of assessment scores and outcomes, closing off employment pathways for many people.

Impairment tables, Job Capacity Assessments and other Centrelink assessments are not fit-for-purpose for many people, including people with intellectual disability. Centrelink, and government systems generally, need to improve their understanding of people with intellectual disability and how to engage and communicate with this community.

Navigating the system

The DSP system is inaccessible and unnecessarily complex. It places huge stress on people with disability and their families and carers and it discriminates against and disadvantages people who are unable to navigate the system.

Information is very complex and largely inaccessible to people with intellectual disability - and many families and carers.

¹ The Speak Out resource, *Communication – it's not a spectator sport* describes acquiescence as follows: "Many people with intellectual disability say 'yes' to questions or accept and agree with things, regardless of what has been asked, and often without really wanting to. This is called acquiescence. People with intellectual disability often mask their communication difficulties to avoid the stigma of being labelled as having a disability. It is very common for people to adopt a passive communication style, allowing the more powerful person to control the conversation."

People with intellectual disability told us:

“My sister did it for me a long time ago.”

“It was too much paperwork.”

“Mum helped me.”

“I took many hours and I had to do a long test about my ability to work and my IQ. I needed my Mum to help and she had to take time off work to do that.”

Rules, processes and requirements are complex and convoluted – for anyone. Advocates and families told us:

“It’s difficult breaking that information down... It’s medico-language that even I, as an advocate, am not always able to interpret.”

“Centrelink staff give inconsistent or differing information regarding what supporting evidence is required.”

Emotional impact

Many people commented on the emotional impact of trying to get DSP and dealing with Centrelink.

“It felt bad because it was showing up my disability which I hate talking about.”

“Trying to prove disabilities for DSP is soul-destroying. The hoops you have to jump through to prove incapacity is awful.”

“The staff don’t like me because we tried to fight them (to get DSP). I still hate going to my local Centrelink office because there still people there that I know.”

“...we don’t even acknowledge the emotional hurt people experience going through the assessments. To know they’ve tried their hardest, exhausted themselves in the process... the feelings of shame are overwhelming.”

Remote Assessment

Families living in regional and remote areas told us about their experiences applying for the DSP. It is difficult and costly to get reports; there just aren’t the specialists available.

Parents said that assessments done over the phone meant that assessors don’t get the full scope of a person’s disabilities.

“I am extremely opposed to Job Capacity Assessments done over the phone. I feel it disadvantages the client as the interviewer cannot see the body language and anxiety of the person they are interviewing, and will miss visual indicators of the client struggling to answer.”

While phone assessments were previously used mainly due to location, since Covid-19, they are more common and look likely to be used more for the foreseeable future.

Conclusion

The comments from people with intellectual disability, their families, advocates and other supports show that the issues with applying for the DSP are much broader than just the Impairment Tables. IA urges the Department of Social Services to review the Impairment Tables in the context of interrelated issues as outlined above. It is not enough to simply have Tables that effectively measure 'functional impairment', the process of being measured must be made more accessible.